

Developmental Disabilities Planning Council/Review of State Services and Supports
Contract #: ISA DDPC 01-04-2010

Approximately 30,815 people with developmental disabilities (DD) are served by the Arizona Department of Economic Security's Division of Developmental Disabilities (DES/DDD) on the basis of four diagnostic categories (cognitive disability, autism, cerebral palsy and epilepsy) and substantial functional limitations.¹ Certain at risk infants, toddlers and young children may also be eligible. Service distribution is roughly proportional to the overall distribution of population within Arizona's six districts. In terms of ethnicity and race, the numbers are also reflective of the general population patterns in Arizona.²

The DDD data indicate that 26,719 (87%) individuals with developmental disabilities in Arizona reside with a family caregiver or spouse or have their own households, while 2,455 (8%) live in a developmental disability group home and another 842 (3%) live in what DDD calls an adult developmental home.

There are other important demographic trends affecting the DD services and supports landscape. Between 1980 and 2006, Arizona's Hispanic population increased from 444,000 to 1.3 million, a remarkable 192% increase.³ There are twenty-one federally recognized Native American tribes in Arizona, each with its own unique culture and internal governmental structure. In the tribal communities, health and social services are available but limited in scope. Potential barriers to services include second language issues and cultural beliefs about health and disability.

Demand for developmental disability (DD) services and supports at both the state level and national level continues to grow, encouraged by demographic, legal, and political forces.⁴ At the same time, Arizona's budget crisis has resulted in unprecedented reductions in funding and services across health, education and human service agencies.

AGENCIES AND ORGANIZATIONS PROVIDING SERVICES TO PEOPLE WITH DD

Department of Economic Security (DES)

Agency: The Division of Developmental Disabilities (DDD)

Eligibility: A child from birth through age five with a developmental disability or significant delay in one or more areas of development (language, cognitive, social, physical, self-help) that could lead to a developmental disability; or a condition that is likely to result in a developmental disability without services. Children age six and over must have cerebral palsy, epilepsy, autism, or a cognitive disability which is identified before age 18, likely to continue indefinitely, and causes substantial limitations in three or more of the following life functions: receptive and expressive language, learning, self-direction, self-care, mobility, capacity for independent living, and economic self-sufficiency.

Services: Attendant care, day treatment and training, employment supports and services, rehabilitation, home health aide, home modification, home nursing, housekeeping, intermediate care

¹ Based upon Division data shared with the Sonoran UCEDD in August of 2010.

² U.S. Census Bureau, *State and County Quickfacts*, 2009. Retrieved from <http://quickfacts.census.gov/qfd/states/04000.html>

³ Albecht, D. E. (2008). *The State of Arizona. Population Brief: Trends in the Western U.S.* Logan, UT: Western Rural Development Center. Retrieved from http://wrdc.usu.edu/files/uploads/Population/Arizona_WEB.pdf.

⁴ Braddock, D., Hemp, R., & Rizzolo, M. C. (2008). *The State of the State in Developmental Disabilities* (Seventh Edition). Boulder: University of Colorado, Coleman Institute for Cognitive Disabilities and Department of Psychiatry.

facilities for cognitive/intellectual disability, medical services, nursing facilities, respiratory therapy, respite, therapies - occupational, physical and speech, transportation (non-emergency).

Barriers: Budget cuts have required DDD to terminate some home and community based services for 300 children and 400 adults with DD who are not eligible for services funded through the state's Title XIX Medicaid program. These services were paid entirely out of state funds.

Department of Economic Security (DES)

Agency: Division of Children, Youth, and Families/Temporary Assistance to Needy Families (TANF)

Eligibility: Single parent families, with a strict time limit and work requirement. Some individuals with DD are eligible if they fall within the categories.

Services: Financial assistance to eligible families; assistance in training and finding work; and some child-care assistance if the parent is working.

Barriers: Persons with DD may need more assistance with work. Parents of children with DD often have difficulty working and need day care for special needs. An estimated 10,000 people are losing eligibility for temporary cash assistance as the time limit for assistance is cut back to 36 months from 60.⁵

Department of Economic Security (DES)

Agency: Arizona Early Intervention Program (AzEIP)

Eligibility: Children from birth until age three who have a developmental delay in which the child has not reached 50 percent of the developmental milestones expected at his or her chronological age, in one or more of the following domains: Physical, cognitive, language/communication, social/emotional, and adaptive self-help.

Services: Assistive technology, audiology, family training, counseling and in home visits, health services, medical services only for diagnostic or evaluation purposes, nursing services, nutrition, occupational therapy, physical therapy, psychological services, service coordination, social work, special instruction, speech-language therapy, vision services, and transportation (to enable the child and family to participate in early intervention services).

Barriers: Reports of lack of sufficient early intervention service providers in rural areas and too few qualified professionals who can diagnose autism across the state. Fees for early intervention services based on family income and family size. ALTCS, Indian Tribes, and less than 199% poverty level don't have to pay.

Department of Economic Security (DES)

Agency: Rehabilitative Services Administration/Vocational Rehabilitation (RSA/VR)

Eligibility: Disability must be a barrier to obtaining or retaining employment and the provision of vocational rehabilitation services allows the individual to become independently employed.

Services provided: Education, training and job development services may include assistive technology or services that may be needed to obtain or retain employment, job coaching, and re-training or education to secure and/or keep employment.

Barriers: RSA/VR is operating under an Order of Selection under which, depending on budget issues, either all categories are closed or only Priority Group One clients (eligible individuals with

⁵ Center on Budget and Policy Priorities, "An Update on State Budget Cuts At Least 46 States Have Imposed Cuts That Hurt Vulnerable Residents and the Economy." Retrieved from: <http://www.cbpp.org/cms/?fa=view&id=1214>

the most significant disabilities) get services. Most DD clients fall under Priority Group One. As of March 12, there are 2,118 individuals in Priority Group One on the waiting list, with some releases expected in coming weeks and a goal of all individuals in Priority Group One released from the waiting list by June. Some DD individuals will not be found eligible for VR because they are considered unable to become competitively employed.

Department of Economic Security (DES)

Agency: Division of Aging and Adult Services

Eligibility: Individuals 55 and older as well as adults with disabilities. While not DD specific services, older individuals with DD and their parents would be eligible.

Services: Independent Living Supports that provide a range of services and supports to older adults and eligible persons with disabilities. Programs include AZ Links, the Family Caregiver Support Program, Home and Community Living Supports, and Nutrition Services.

Barriers: The FY 2010 and FY 2011 state budgets have seen reduced funding for aging and adult services, including cuts to Independent Living Supports and in-home assistance for 700 older Arizonans that allows them to remain in their home instead of moving to a nursing home.

Department of Health Services (DHS)

Agency: Office for Children with Special Health Care Needs (OCSHCN)

Eligibility:⁶ Children who have or are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Services: OCSHCN provides medical and related services through clinics to children who are at risk for developmental delay, metabolic/genetic disorders, or hearing impairment.

Barriers: Only AHCCCS eligible children are receiving services. 19% of children with special health care needs in Arizona are reported to have at least one unmet health care need during the last 12 months. This rate is 2.5 times higher than the rate for other children. Proposed cuts federally to Maternal Child Health Title V may affect services.

Department of Health Services (DHS)

Division of Behavioral Health Services (DBHS)

Agency: Tribal and Regional Behavioral Health Authorities (RBHA's)

Eligibility: People who are Title XIX (AHCCCS) or Title XXI Children's Health Insurance Program (CHIP-Federal) (Kids Care-Arizona) eligible and have certain behavioral health conditions that can benefit from medically necessary behavioral health services. Others identified as having a serious mental illness may also be eligible. ADHS/DBHS has Intergovernmental Agreements (IGAs) with some of Arizona's American Indian Tribes to deliver behavioral health services to persons living on the reservation.

Services: Prevention services provide information and skill building techniques to help clients lead a happy life. Evaluations help determine what individual issues may be and what to do about them. Treatment includes such things as counseling, crisis response, medications, and in-home supports.

⁶ Much of the data for this section and following sections was taken from the recently released *Maternal Child Health Assessment* report issued by the Maternal Child Health and Children with Special Health Care Needs programs.

Barriers: State budget cuts have meant substantial reductions to the behavioral health services that are provided to non-Title XIX (state-only) populations. Greater needs are being reported in Tucson following the January 8, 2011 shootings.

Agency: Arizona Health Care Cost Containment System (AHCCCS)

Eligibility: Arizona's Medicaid agency provides payment for health care for people who are very low income (100% poverty level or below), including people with developmental disabilities on SSI.

Services: Coverage includes Acute Care Services. Doctor's visits, immunizations, prescription coverage if no Medicaid, lab and x-rays, specialist care, hospital services, transportation to doctor, emergency care, pregnancy care, surgery services, physical exams, behavioral health, family planning, and dialysis.

Barriers: AHCCCS is only available to people at the very bottom of the economic stratum: generally monthly income cannot exceed \$903 for one person or \$1,215 (100% of the federal poverty level) for two people. Many individuals who are not eligible for or able to afford employer related health insurance still make too much money to qualify for AHCCCS. Services have also been cut recently for AHCCCS participants. In addition, proposed budget cuts would reduce eligibility, cutting an estimated 280,000 people currently on AHCCCS. While these cuts will not affect DDD clients who are eligible for Title XIX support, it could have an impact on low-income people who meet the federal definition of developmental disability but whose income exceeds the proposed new AHCCCS limits.

Agency: Arizona Long-Term Care System (ALTCS), part of AHCCCS

Eligibility: Individuals who are elderly, physically disabled or developmentally disabled must meet functional and income requirements, and be at risk of institutionalization.

Services: Long-term care and case management, in home services, habilitation (if DD) and a broad range of other services including day treatment and job supports. It also pays for nursing home if institutionalized.

Barriers: Effective October 1, 2010, AHCCCS benefit changes eliminated a wide range of acute care medical services previously available to ALTCS members, including most dental care and services, well doctor visits, bone anchored hearing aids and cochlear implants, and more. Other potential cuts include the Freedom to Work program which helps individuals with disabilities between 16 and 65 who want to work but are worried about losing medical and Social Security benefits.

Arizona Department of Education

Agency: Special Education, Exceptional Students Division

Eligibility: Age 3-5, pre-school and up to age 22 - children who need special education and/or related service in order to obtain free, appropriate public education.

Services: Specialized designed instruction and related services, including transition.

Barriers: In resource limited environments it may be more difficult for schools to provide inclusion and other services to children with DD and decreased state funding for education overall.

Agency: Arizona Department of Corrections

Eligibility: Incarcerated people with DD under age 22 are eligible for special education.

Services: Special education services including specialized instruction and related services pursuant to an IEP.

Barriers: Lack of identification or knowledge of the extent and characteristics of the DD population in prison.

Agency: Arizona Department of Juvenile Corrections

Eligibility: Youth with DD are eligible for educational services under an IEP, as well as a variety of counseling and rehabilitation services.

Services: The ADJC has policies and procedures in place to provide programs and related services for students who are eligible under the Individuals with Disabilities Education Act (IDEA).

Barriers: HB2376, pending in the State Senate as of March 26, 2011, would retain the Department of Juvenile Corrections until July 1, 2012. Legislation in 2010 established the Commission on Juvenile Corrections Reform to make recommendations regarding the juvenile corrections system.

Federal Programs

Social Security Administration

Agency: Supplemental Security Income (SSI)

Eligibility: Adults or children who are disabled or blind, have limited income and resources, meet living arrangement requirements, and are otherwise eligible. Also children, birth to 18, who are seriously disabled and have little or no income and resources.

Services: The monthly payment varies up to the maximum federal benefit rate, which may be supplemented by the State or decreased by countable income and resources. The monthly maximum Federal amounts for 2011 are \$674 for an eligible individual and \$1,011 for an eligible individual with an eligible spouse.

Barriers: In up to half the cases, individuals are initially denied SSI and only through the appeals process are found to be eligible. Reconsiderations and appeals can take up to two years. Eventually, if found eligible, the applicant will receive all back benefits.

Agency: Social Security Disability Insurance (SSDI)

Eligibility: Worker must earn sufficient credits based on taxable work to be "insured" for Social Security purposes. Disability benefits are payable to blind or disabled workers, widow(er)s, or adults disabled since childhood, (based on the credits of a disabled worker who is deceased) or are otherwise eligible. SSDI pays benefits to people who cannot work because they have a medical condition that is expected to last at least one year or result in death. SSDI does not give money to people with partial disability or short-term disability.

Services: The amount of the monthly disability benefit is based on the Social Security earnings record of the insured worker.

Barriers: Most individuals who are developmentally disabled would not be eligible for SSDI because of limited work history unless they are eligible through a parent. They are usually eligible for SSI if they have limited income and resources.

The *Work Opportunity Tax Credit* is a federal tax credit incentive that Congress provides to private-sector businesses for hiring individuals from twelve target groups who have consistently faced significant barriers to employment, including people with disabilities who are referred by Vocational Rehabilitation. The main objective of this program is to enable the targeted employees to gradually move from economic dependency into self-sufficiency as they earn a steady income and become contributing taxpayers, while the

participating employers are compensated by being able to reduce their federal income tax liability.

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Advocacy/Non-Profit Organizations/Academic/Other (sampling – many others in State)

The Arizona Center for Disability Law, Arizona Developmental Disabilities Planning Council, Sonoran UCEDD, and Institute for Human Development are partner organizations that together form the Arizona Developmental Disabilities Network.

Arizona Center for Disability Law serves as the state's designated protection and advocacy system for individuals with disabilities, and provides legal and advocacy services, training, information and referral in priority areas, which include special education, employment, access to health care services, and abuse and neglect prevention/investigation.

Arizona Developmental Disabilities Planning Council engages in advocacy, capacity building and systemic change to increase inclusion and involvement in the community, and strives to achieve the essence of the Developmental Disabilities Act by promoting self-determination, independence, productivity and integration to support persons with developmental disabilities and their families in all facets of community life.

University Centers for Excellence in Developmental Disability Education, Research, and Service

Sonoran UCEDD (University of Arizona) has programs and projects that assist individuals with developmental disabilities in navigating life transitions, and promotes services and supports in Hispanic communities along the Arizona/Mexico border. It provides services to diverse linguistic and ethnic populations, and develops and implements family support projects.

Institute for Human Development (Northern Arizona University) provides support and services to individuals with disabilities and families across northern Arizona, including Native American tribes and families. It administers family support and self-determination projects, as well as early intervention services to young children and families across the State.

Arizona Disability Advocacy Coalition acts as a catalyst to engage individuals with disabilities, their families and organizations that serve them in advocacy efforts that promote public policy which enhances the choice, dignity, rights and responsibilities of people with disabilities.

Arizona Technology Access Project provides the following to people with disabilities, their family members, and service providers: equipment demonstrations, short-term equipment loans, equipment reutilization, alternative financing, and public awareness,

training and technical assistance including transition services and interagency coordination/ collaboration.

Autism Society chapters in Tucson, Phoenix and Flagstaff reach out to individuals with autism and their families with information, support, and encouragement.

Epilepsy Foundation of Arizona works to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through research, education, advocacy and services.

Linkages works as the liaison between area businesses with employment openings and participating rehabilitation providers with qualified people ready to work, seeking to ensure that all people are given the opportunity to perform and be valued.

Partners in Policymaking is an innovative, competency based leadership training program for adults with developmental disabilities and parents of young children with disabilities designed to teach best practices in disability, and to teach the competencies of influencing and communication.

People First of Arizona is part of a self-advocacy movement by and for people with disabilities offering experience through participation.

Pilot Parents of Southern Arizona is committed to providing encouragement and support to families who have children with special needs so that their children can reach their maximum potential within the family and society.

Raising Special Kids provides training and information to parents with children and youth with special health care needs, as well as the professionals who serve them.

Self Advocacy Coalition of Arizona enhances the rights and responsibilities of individuals with disabilities by establishing and maintaining working partnerships with individuals and advocacy groups.

Southwest Autism Research and Resource Center sets forth, promotes and facilitates best practices for early intervention and the long-term care of individuals with autism spectrum disorders through integrative research, educational outreach, model programs and collaborative initiatives.

Statewide Independent Living Council provides the following to individuals with disabilities: independent living, home modification, travel training, person care attendants, advocacy, and employment services. There are five Centers for Independent Living in Arizona: *ABIL - Arizona Bridge to Independent Living* in Phoenix, *ASSIST! to Independence* in Tuba City, *DIRECT Center for Independence, Inc.* in Tucson, *New Horizons Independent Living Center* in Prescott Valley and *S.M.I.L.E. - Services Maximizing Independent Living Empowerment* in Yuma.

The Arc of Arizona advocates for the rights and full community participation of all people with intellectual and developmental disabilities, working to improve systems of supports and services, connect families, inspire communication and influence public policy.

Tucson Alliance for Autism promotes community awareness and provides diagnostic and therapeutic services for individuals with an Autism Spectrum Disorder (ASD), educates and supports professionals and families on ASD-related issues, and supports and provides resources for families.

United Cerebral Palsy affiliates in Phoenix and Tucson provide support groups for people with disabilities and their family members and friends, share important information and services across the developmental disability community, and advocate for improved services.